GiveWell's notes from meeting of stakeholders for Malawi national schistosomiasis control program, Oct. 18, 2011

We (Natalie and Holden) attended a meeting in Lilongwe for stakeholders in Malawi's schistosomiasis control program funded by DFID, UK through their project named "ICOSA". The meeting included representatives from Schistosomiasis Control Initiative (SCI, represented by Alan Fenwick and Charlotte Gower), the Center for Neglected Tropical Diseases (CNTD) at the Liverpool School of Tropical Medicine (conducting the evaluation for the program, and represented by Maria Rebollo), DFID (financial support for ICOSA), World Vision (supplying 4 million tablets per year of praziquantel for the program), the Malawi Ministries of Health and Education, and district health offices. There were about 20 total attendees. Our notes:

- DFID has allocated 50 million GBP for control of neglected tropical diseases over 5 years, of which £25 million is going through SCI for schistosomiasis control in 8 countries (including Malawi) over five years (ICOSA). World Vision has also offered to donate an annual supply of praziquantel to Malawi for schistosomiasis control. Thus, Malawi is planning a national-level schistosomiasis control program.
- There are other suppliers of praziquantel too, including a grant from GAVI through Malawi's EPI program (our rough understanding is that Malawi projected its EPI program to come in under budget and got permission to use some of its EPI funds for schistosomiasis control).
- The WHO also has a supply of praziquantel available for donating; and Malawi was a
 recipient in 2010. However because the Malawi program is relatively well supplied from
 2010, the WHO will be able to donate its praziquantel elsewhere.
- Of SCI's £25 million GBP from DFID, £15 million is for purchase of praziquantel and equipment including vehicles. Other expenses met by the ICOSA will include mapping and direct financial support to the Malawi government (for delivery costs). The M and E (evaluation) is conducted by staff at SCI and CNTD and the funds are from ICOSA. An independent evaluation funded separately by DFID will be held mid-term.
- The first activity in the meeting was to review the minutes from the previous meeting. These were distributed in printed form and read aloud by a meeting participant. One of the issues that came up last meeting was that World Vision hadn't yet finalized how much praziquantel it would be able to provide. At this meeting, the World Vision representative stated that this still isn't finalized, and will be finalized later.¹
- The second item was to review the schedule for the project and discuss the extent to which it's on schedule. The program is running only slightly behind schedule.²
- The next item was a discussion of experiences from the field where early mass drug administrations had been carried out. The agenda called for updates from the Dedza, Salima, Thyolo and Karonga districts.
 - The Dedza representative spoke first.
 - He reported that PZQ (praziquantel) was administered in 181 schools (out of 239 total eligible). 109k tablets were used, achieving 74% coverage within the treated schools (48% coverage for the district as a whole). They didn't have enough PZQ to do more.
 - He noted that they hadn't had enough stationery to do data collection, so they didn't have the hoped-for data.
 - He reported some convulsions, fainting and vomiting in response to the PZQ - "this scared a lot of children." Some health workers were

¹ Alan Fenwick comments: "(it has since been confirmed as 4 million tablets in 2012)"

² Alan Fenwick comments: "(maybe one month, due to the late arrival of pzq)"

apparently attacked. The meeting chair (from the Ministry of Education) said they would assign a task force to figure out how to stop that from happening again. Prof. Fenwick said this issue was likely due to lack of eating before taking PZQ; he noted that those carrying out mass drug administration should coordinate with school feeding programs when possible, and when this wasn't possible, should provide some food or at least use social mobilization to make sure kids know to eat first. He stated, "An upset stomach is a good sign, it means the PZQ is working, but vomiting is not, it means the PZQ is wasted."

- DFID asked how common school feeding programs are; the response was that about 32% of schools have them. Someone else asked how common the vomiting was, and the representative from Dedza responded that he didn't have stats because he hadn't had stationery.
- The Dedza representative was congratulated for reporting substantive issues and helping people get the information they needed to improve the program.
- The Thyolo representative spoke. Apparently the shipments of PZQ were received, but it wasn't clear that they were intended for mass drug administration (they were interpreted simply as donations), so something happened to the shipments other than what was intended. We (GiveWell) weren't clear on exactly what had happened to the PZQ. There was a discussion of how to prevent this from happening in the future.
- The Salima and Karonga representatives were absent.
- Dr Maria Rebollo (ICOSA M and E Manager) discussed plans for evaluating the program, with a goal of showing its success so that more money can be raised in the future. She stated that they're collecting baseline data for outcomes including coverage (which they consider the main outcome of interest, since treatment with PZQ is already proven to be effective), prevalence of infection, intensity of infection, anemia and improved heights and weights (growth).

GiveWell's notes from conversations with Alan Fenwick on Oct. 17 and 18, 2011

- We asked whether the Oct. 18 stakeholders' meeting (see above) was representative of how such meetings normally go. Prof. Fenwick stated that it was above average, that he was glad people were raising problems in the field, and that he was glad that the program manager has laid out an ambitious schedule.
- Prof. Fenwick said that Merck-Seono in conjunction with WHO had wanted to donate drugs to countries that didn't already have programs and that he had anticipated serious difficulties for such programs due to lack of funds for distribution. He feels that much of the low-hanging fruit for schistosomiasis control programs (in terms of countries where it's likely to work) has been plucked, though the Kenya program (with Deworm the World) is promising and an Ethiopia or Angola program could go well. Angola is fairly wealthy and has a big schistomiasis problem; SCI has assisted Angola to prepare a national plan but funding for implementation have not yet been identified.

³ Charlotte Gower comments: "The PZQ was placed in health centres for distribution/treatment of people reporting symptoms." Alan Fenwick comments: "(SCI's understanding was that they have not been distributed using MDA as was intended due to poor communication – a lesson to be learned (also pls note this lack of communication was before SCI became involved and these are the types of problems we hope to avoid)"

- SCI generally doesn't do water and sanitation programs because of the expense. In Burundi they're beginning to implement water and sanitation programming because they have been successful there with running a deworming program and treating schistomiasis, but soil-transmitted helminth infections remain persistent and need water and sanitation.
- SCI is hesitant to use one-off donations to fund programs that do not have guaranteed funding for them to be continued over the longer run. Donors often want their money to be used as quickly as possible but this isn't necessarily the optimal way to spend it. Right now SCI's top priorities for using moderate amounts of additional funding are
 - Malawi: reaching groups other than schoolchildren, adults at high risk for example.
 - o Senegal: paying for distribution of already-committed praziquantel.
 - Mozambique, where every single person in rural areas, virtually, needs to be treated at least once.
- We asked how SCI had gotten the grants from the Gates Foundation. Prof. Fenwick stated that in 2001 he had seen them announcing plans concerning HIV, malaria, etc. and had emailed them asking whether they'd consider schistosomiasis control as well. They invited him in and he gave a presentation, and was given \$750,000 to explore the possibility of national-level schistosomiasis-control programs. About 7 months into his investigation, he was asked to submit a proposal for executing programs, and was eventually awarded \$30 million.
- Prof. Fenwick stated that he had a track record prior to this from virtually eliminating schistosomiasis in Egypt between 1988 and 2000.
- Prof. Fenwick outlined some specifics on SCI's ongoing activities:
 - The DFID program is projected to be 3 treatments per £1, in 8 countries. Details
 are still being worked out, but the promise is to deliver 75 million treatments in all
 - In Burundi, SCI is supporting both mass drug administration and starting a water/sanitation program. Each year, it treats 500,000 people for schistosomiasis and ~3 million for soil-transmitted helminthes. The Rwanda program is similar.
 - In Yemen, SCI distinguishes between high, medium and low prevalence areas. In high prevalence areas, the Yemen programme treats the whole population for three years and children for five years. In medium prevalence areas, the whole population is treated once, then children every other year. In low prevalence areas, the children are treated every other year. 30 million treatments total are anticipated.
 - In Mozambique, school-age children are the main target group initially.
- We asked where SCI gets its views on which age groups to treat and how often, based
 on the setting. SCI stated that this is largely based on WHO guidelines combined with
 local knowledge, intuition and common sense, though it usually works and SCI collects
 sufficient data to know when it isn't working. In general, in high endemicity areas
 reinfection is a major issue; in lower endemicity areas, a single treatment can be
 sufficient.
- We asked whether there are any important outstanding research questions concerning schistosomiasis treatment. Prof. Fenwick responded that research could help with designing guidelines for where to implement programs for children under five.
- We asked for some more details on delivery costs. Per-diem costs (i.e., rewards to those
 who deliver the drugs) can be a significant part of the delivery costs: An example could
 be \$10-20 for a one- or two-day training for teachers or health surveillance assistants.
 We estimated (informally) that these could be up to half of delivery costs and Prof.
 Fenwick said that sounded about right. Other expenses include startup costs (mapping,

- vehicles), public communication (e.g., broadcasting about upcoming programs over the radio), transportation of drugs to districts, development of IEC (health education) materials, other social mobilization (e.g newspapers, village criers as appropriate).
- Prof. Fenwick stated that praziquantel can be surprisingly hard and expensive for people in low-income areas to seek out for themselves and afford because of the low demand he stated that a pharmacy might charge \$20 for a course, and that this is outrageous.

GiveWell's notes from its visit to a primary school deworming on Oct. 19, 2011

The site was about 30 minutes' drive from the hotel in Lilongwe. At the site, I (Holden) saw:

- A school
- A building that appeared dedicated to a school feeding program (pictured), bearing the name of the Foundation for Irrigation and Sustainable Development
- A PlayPump, on which children were playing for most of the day (though not in the morning when I arrived). It was only partly working the water was being pumped more slowly than normal, according to the teacher I spoke with and there was a USAID sign by it (pictured) giving instructions for texting for help if it broke. The teacher I spoke with said it had been partially broken for a couple of weeks, that the text had been sent, and that a repair was expected (in the past repairs had generally taken a few months). I also saw a normal hand pump nearby later in the day.
- Multiple latrines (8 for girls, more for boys; these are pictured).
- A USAID radio attached to a solar panel and a crank. Apparently it can be powered by either. I tried listening to some music; the music faded in and out.
- The teacher I spoke with stated that there is another school 1km away and another one 3km in the other direction.

I wandered a bit at one point and saw more NGO signs, brick houses with thatched roofs and brick houses with metal roofs (all pictured).

My understanding of how the mass drug administration worked:

- In the classrooms, the children got their names written down in a notebook. Outside the classrooms, children not enrolled in school had formed a crowd and were getting their names written down. Heights were measured, to determine dosage (height is a proxy for weight).
- The person running the day's program went into each classroom and talked to the class for 10-20 minutes. It was in another language and I only got part of it translated.
 - He was explaining that it was OK if they got an upset stomach, and that this would help them be healthier.
 - He was also telling them how to avoid schisto in other ways, such as wearing plastic on their legs when they went in the water.⁴
- The school feeding program was active (pictured), and I believe that the process was for all children to eat before taking praziquantel.
- After all the classrooms had received the initial speech, the staff leading the program went into each classroom and carried out the drug administration. They called the name

⁴ Charlotte Gower comments: "He was also discussing that haematuria (blood in urine) was a sign of schistosomiasis, and the urinating in the water should be avoided. He was also explaining the immediate and longer term effects of schisto on health."

of each registered child. If a child stood up in response, they would call out the dose, and the nurse sitting at the front of the classroom would hand the child pills and the child would put the pills in his/her mouth, scoop some water from the bucket at the front of the classroom, and drink the water. Some children wandered around with their pills before taking them, but all did eventually take the pills as far as I could tell. We have a video of this part of the process.

- A lot of the children weren't present when their name was called, so they were skipped. A
 lot of children also weren't on the register, so at the end, they lined up and were
 registered and measured for height. The dose pole was brought into the classroom for
 this part. ⁵
- I only saw one teacher present, and did not see any instruction;⁶ the main activity of the day was drug administration.
- Since this is a high-risk area, this time (the first time) they are treating everyone. In the future it will just be schoolchildren. According to SCI representative Charlotte Gower, "I don't have the official figures yet but the overall treatment numbers were approximately 1400. Of these approximately 1000 were SAC [school-age children] and the coverage of enrolled children (based on the registers) was approximately 75%. I was advised informally that approximately 50% of the community (adults and non-enrolled children) had also attended treatment. Target coverage according to WHO guidelines is 75% for schoolchildren and >25% for high risk adults."
- SCI representative Charlotte Gower and I discussed mapping. This school was surveyed in 2007 using microscopy. What this means is that they inspect urine under a microscope for eggs. If they see one egg, they mark the child as having schistosomiasis and move on - it takes longer (and is thus more expensive) to gauge how heavy the schistosomiasis is, which would require looking at all the slides and counting the eggs. They can also look for blood in the urine using a dipstick (except in severe cases, this blood is not visible to the naked eye but can be detected by dipstick) and this is easier but it's a higher infection intensity threshold since not everyone with eggs in the urine has blood in the urine. The WHO recommends surveying 10 schools / 50 kids per school, per target area (in Malawi a "target area" is a district since the terrain is pretty homogenous, but in other countries they might divide it up more); SCI might survey 20 schools instead. The sample sizes are being calculated by a senior SCI biostatistician, in order to develop a robust estimate of prevalence, with confidence limits, to allow treatment decisions to be taken. In Malawi SCI is planning a stratified survey to determine whether it is possible/desirable to implement at below-district level based on ecological differences within districts. The goal of mapping is to provide a cost-effective way to determine how much treatment is needed and the frequency of treatment required.

⁵ Charlotte Gower comments: "Registration was carried out in the school approximately one week before the MDA to speed up the process."

⁶ Alan Fenwick comments: "(there was a holiday this week – this was a special day)"